

## **Primary Progressive Aphasia - A New “normal”**

By Justine Leshikar

When I was a junior in high school, I decided that I wanted to quit the cheerleading squad in the middle of football season. I informed my father of this decision and he said, “Absolutely NOT. Tripp’s (our last name) are NOT quitters.” That statement was informally coined as our family motto and has remained our theme over the last 5 years as we have navigated through my father’s speech and language difficulties and what we now know is a diagnosis of Primary Progressive Aphasia- Logopenic subtype.

My father is a retired Commander in the United States Navy Reserve, a retired healthcare consultant who specialized in strategic planning, a devout Catholic, faithful husband of 39 years to my mother, proud father of 2 sons and 2 daughters and a REALLY proud Papa of 8 grandchildren. He was always a very well spoken man and was the guy you wanted proofreading your resume or essay. For the past 18 years, he worked for a company where he had a very stressful job- but he loved it and felt very passionate about what he was doing.

In the summer of 2009, my mom started noticing that my dad would sometimes have trouble coming up with a word or he would have a moment where it seemed like he was talking “gibberish.” Both of my parents would kind of laugh it off and blame it on my dad being stressed and tired from his demanding work schedule. These symptoms would come and go for the next year and half until his speech difficulties were no longer something that just happened “sometimes” or “when he was stressed.” We became worried that perhaps he had suffered a TIA (transient ischemic attack) or a mini stroke and his language difficulties were a result of that. Once he had received a clear MRI from his neurologist and was basically told, “There is something going on- but we just aren’t sure what it is” I knew we needed to dig deeper for answers.

Ironically, I am a speech-language pathologist- so seeing my father struggle with various aspects of language was incredibly painful and frustrating for me. After reaching out to an esteemed professor from my graduate school, she encouraged us to see Dr. Keith Josephs and Dr. Joseph Duffy at the Mayo Clinic in Rochester, MN to seek more information and a possible diagnosis. In May 2012, 3 years after my father’s symptoms began; we received a diagnosis of early onset Primary Progressive Aphasia- Logopenic subtype.

Northwestern University Cognitive Neurology and Alzheimer’s Disease Center describes PPA as, “a form of cognitive impairment that involves a progressive loss of language function. PPA begins very gradually and initially is experienced as difficulty thinking of common words while speaking or writing. PPA progressively worsens to the point where verbal communication by any means is very difficult. The ability to understand what others are saying or what is being read also declines. In the early stages, memory, reasoning and visual perception are not affected by the disease and so individuals with PPA are able to function normally in many routine daily living activities despite the aphasia. However, as the illness progresses, other mental abilities also decline.” Receiving this diagnosis was a huge blow to our family. The degenerative nature of the disease is very frightening; and because PPA is still

quite rare, with not a lot of research available about it, we were left to think the worst of what could happen to my father.

Here's where that motto, "Tripp's aren't quitters," came into play. My father (and mother) had a period of time where they felt the multitude of emotions that comes with finding out about a disease with no cure. But after processing through those emotions, they made a decision to live one day at a time, purposefully and with positivity. My father, who is an extremely goal oriented individual, found that planning out his week with activities to help maintain his language skills, volunteer work, and exercise has been extremely helpful. He participates in two separate Communication Cafes via the Aphasia Toolbox website and he and I work together weekly for 60 minutes doing various treatment activities via Skype (we live in separate states). He works as a volunteer twice a week at an outreach center that disperses medical supplies to 3<sup>rd</sup> world countries and exercises daily. He also attends church twice a week and participates in various activities at church. He makes a choice every day, to remain engaged in life and with other people.

Since my father's diagnosis a little over 2 years ago, we have had to learn to live in an ongoing state of a "new normal." Due to the fact that PPA is degenerative in nature, my father and our family are navigating through the changes that are taking place in his ability to process information and communicate with others. Some days are really hard. Other days are sad because of the changes that have taken place in my father's ability to communicate. But MOST days are really GOOD- because my father's new normal isn't bad- it is just *different*. I know that my father has a great faith in God that carries him forward and he is incredibly grateful for his wonderful wife, pretty great kids and super awesome grandchildren ☺

The best advice I can provide loved ones of individuals with PPA is to find support, whether that is with other individuals with PPA or a general aphasia treatment group. If those resources are limited, educate close family members and friends, so that a safe network is in place. Know that some days are going to be really hard and you will miss parts of the way your loved one with PPA "used to be," but also know and believe with all of your heart that person still remains. Every day is new- seize the opportunity to live positively and create memories, living in your "new" normal.

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